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A qualitative exploration of patients' experiences, needs, and expectations regarding online access to their primary care record

Brian McMillan*[1], Gail Davidge[1], Lindsay Brown[1], Moira Lyons[1], Helen Atherton[2], Rebecca Goulding[1], Freda Mold[3], Rebecca Morris[1], Caroline Sanders[1]

1. Centre for Primary Care and Health Services Research, University of Manchester, UK
2. Warwick Medical School, University of Warwick, UK
3. School of Health Sciences, University of Surrey, UK

*Corresponding author: Dr Brian McMillan, Centre for Primary Care and Health Services Research, Suite 3, Floor 6, Williamson Building, Oxford Road, University of Manchester, England, M13 9PL. Tel: 0161 2757656, Fax: 0161 2757600

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ABSTRACT

Objectives: Primary care records have traditionally served the needs and demands of clinicians rather than those of the patient. In England, General Practices must promote and offer registered patients online access to their primary care record, and research has shown benefits to both patients and clinicians of doing so. Despite this, we know little about patients' needs and expectations regarding online access to their record. This study explored what patients and carers want from online access to their electronic primary care health record, their experiences of using it, how they would like to interact with their record, and what support they may need.

Design: Focus groups and semi-structured interviews using purposive sampling to achieve a good sociodemographic spread. Interviews were digitally audio-recorded, transcribed and coded using an established thematic approach.

Setting: Focus groups and interviews were conducted in community settings in the UK.

Participants: Fifty four individuals who were either eligible for the NHS Health Check, living with more than one long-term condition, or caring for someone else.

Results: Participants views regarding online access were categorised into 4 main themes: awareness, capabilities, consequences, and inevitability. Participants felt online access should be better promoted, and suggested a number of additional functions, such as better integration with other parts of the healthcare system. It was felt that online access could improve quality of care (e.g. through increased transparency) but also have potential negative consequences (e.g. by replacing face to face contact). A move towards more online records access was considered inevitable, but participants noted a need for additional support and training in using the online record, especially to ensure that health inequalities are not exacerbated.

Conclusions: Discussions with patients and carers about their views of accessing online records have provided useful insights into future directions and potential improvements for this service.

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Strengths and limitations of this study

- This is the first UK based study to explore the experiences, needs, and expectations of patients regarding online access to their primary care record, and to discuss the implications for the development of these services.

- Purposive sampling was employed to ensure a good sociodemographic mix, with individuals from urban and rural areas, and varying degrees of digital and health literacy.

- Patient and public participation in the research ensured it remained patient focussed and included views from seldom-heard groups.

- A mixture of focus groups and one to one interviews enabled exploration of shared experiences and understandings whilst also allowing further probing of minority or controversial opinions and discussion of sensitive issues.

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INTRODUCTION

The GP Contract in England states all patients should have online access to their full primary care record. [1] Whilst this has not been fully implemented, 24% of patients in England have signed up for online records access (ORA)[2] via the NHS App or other NHS-approved service.[3] Systematic reviews examining ORA have identified a number of potential benefits and drawbacks.[4, 5, 6] Patients can use ORA as an aide-mémoire, to help prepare for their next appointment,[7, 8] and report that it saves time by reducing the number of telephone calls and appointments required.[4, 7] ORA can increase patients' feelings of autonomy,[9] enable them to spot and correct medication errors,[4, 6] and positively impacts on clinical measures such as HbA1c.[6] However, clinicians have expressed concerns that ORA could cause unnecessary anxiety, increase complaints, and threaten confidentiality and security. [5] Other concerns relate to: widening health inequalities, risk of coercion, and increased clinician workload.[10]

Research has looked at what patients do with ORA and its impact on patient satisfaction and engagement. However, there has been little research examining what patients *want* from ORA. Overlooking patients' needs and expectations may prevent patient ORA from achieving its full potential. Only three qualitative studies have examined what patients want from ORA,[11, 12, 13] indicating they want it to: 1) be secure and trustworthy, 2) act as a communication aid, 3) be more interactive, 4) serve an educational function, 5) serve practical functions. These studies identified the importance of ORA aiding communication between patients and healthcare professionals (HCPs), other family members, carers, or between HCPs. Patients would like to be able to write into their record,[12, 13] and expressed a desire for decision aids,[11] and lifestyle management with signposting to services.[11, 12] Sought after educational functions included plain English explanations of medical terms,[12, 13] and practical functions including booking appointments,[12] viewing test results,[12, 13] and accessing information needed to complete benefit applications.[12]

Although these qualitative studies have started to identify what patients want from ORA, only one was primary care based and conducted in the UK, and was carried out over 16 years ago examining a significantly different service than is available today.[13] The authors noted that "working in partnership with patients to develop systems is vital to their

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success".[12, p38] To achieve this, we need to ascertain what patients would like from ORA rather than simply asking them to evaluate systems that already exist.

Through our Patient and Public Involvement and Engagement (PPIE) work[14] and previous reviews,[4, 15, 16] we identified three diverse groups likely to have different needs and expectations of ORA: those eligible for the NHS Health Check[17] who value ORA to understand how they might maintain good health[14] and those with multimorbidities and carers, who value it for managing their conditions or the conditions of those they care for.[4] This study therefore aims to explore patients' and carers'

- awareness and experiences of ORA
- views and beliefs regarding ORA
- expressed needs and expectations regarding ORA, including required support.

METHODS

Focus groups and semi-structured interviews were conducted in community settings in the UK.

Sampling and recruitment

A purposive sampling strategy was employed to achieve maximum variability for factors known to impact ORA, such as age, sex, socioeconomic status, and ethnicity.[18] Recruitment methods included utilising the Greater Manchester Clinical Research Network (CRN), approaching community organizations, and snowballing. A participant information leaflet described the study in detail and listed the eligibility criteria (see Appendix 1). Informed written consent was obtained, and focus groups were held until the research team considered that data saturation was approaching,[19] at which point recruitment switched to semi-structured interviews to explore issues raised in greater depth. Recruitment ceased when no new or discordant themes were identified.

Data collection methods

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A total of 11 focus groups and 9 interviews were conducted. The topic guide (Appendix 2) covered five main areas regarding ORA: awareness; experiences; views; needs and expectations; and perceptions of the future. The focus groups and interviews lasted 30-60 minutes, were digitally audio recorded, and transcribed by a university approved service.

Patient and public involvement

The topic guide was developed following observations of clinical consultations at a practice where patients have full ORA, a patient and public involvement and engagement (PPIE) workshop,[14] and discussions with the Primary Care Research in Manchester Engagement Resource (PRIMER) group, two members of which are co-authors of this paper (LB & ML).

Data analysis

Transcripts were anonymised, imported into QSR NVivo 12,[20] and checked for accuracy. Thematic analysis was employed, involving six phases; data familiarization; coding; identification of candidate themes; review and revision of themes; definition and naming of themes; analysis and interpretation of patterns across the data.[19] Discussions amongst the research team helped identify key issues, verify themes, and ensure consistency of coding. We sought to enhance dependability of our findings by involving two members of the public (LB, ML) in two workshops examining the process and product of the study.

RESULTS

Demographics

A total of 27 women and 27 men aged between 21 and 87 years (mean = 59.0; SD = 15.4) participated. We conducted 11 focus groups totalling 36 participants, and 9 individual interviews (see Table 1).

Themes

Patients' and carers' views of ORA concerned four main themes: *1. Awareness, 2. Capabilities*, *3. Consequences*, and *4. Inevitability*.

1. Awareness of online records access

Less than half the participants were aware of ORA. Those who were reported it had been promoted by their GP surgery or had heard of it by word of mouth. Some felt they had no reason to use ORA, found it easier to find information by other means, or felt accessing

Table 1. Participant demographic characteristics (N=54)

Characteristic	n	%
Self identify as carer	19	35.2
>1 long-term medical condition	24	44.4
Eligible for NHS Health Check	30	55.6
Aware of ORA	23	42.6
Previously used ORA	10	18.5
Frequency of internet usage		
Frequently	41	75.9
Occasionally	10	18.5
Never	3	5.6
Ethnicity		
White	43	79.6
Asian	4	7.4
Black	7	13.0
Education		
Degree level	12	22.2
Further education	7	13.0
School to 16 years of age	25	46.3
School to ≤ 16 years of age	10	18.5
Occupation		
Retired	19	35.2
Professional	8	14.8
Sales/customer service	4	7.4
Caring/leisure/other	13	24.1
Admin/secretarial	1	1.9
Associate/technical	2	3.7
Self-employed	3	5.6
Not working	4	7.4
Index of multiple deprivation [26]		
Deciles 1-3 (most deprived)	16	29.6
Deciles 4-7	17	31.5
Deciles 8-10 (least deprived)	21	38.9
Rural-urban classification [27]		
Urban	32	59.2
Suburban	9	16.7
Rural	13	24.1

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medical records was best left to HCPs. Some expressed annoyance that they had not been informed about ORA, whilst others stated that learning about the service had not made them any more likely to use it. Participants felt ORA was poorly advertised, and suggested promoting it via media advertisements, posters in surgeries, and during GP consultations.

2. Capabilities of online records access

Access to information

Participants reported ORA enabled them to view: test results, medication lists, allergies, immunizations, appointment details, problem lists, secondary care letters, and consultation notes, but expressed dissatisfaction with the content, detail, and presentation of the information. Suggested improvements included: direct links to sources of support, more information about the HCPs providing care, better integration with other services, full retrospective access, easier and more consistent access to information, use of plain English, and links to trusted sources of information. Several wished to access all their health and care records via one fully integrated system.

Enabling active involvement

ORA enabled participants to be more actively involved in their own health and care by facilitating: self-monitoring, self-education (e.g. looking up meanings of terms seen in record), self-reassurance, appointment preparation, use of the record as an aide-mémoire or motivational tool, paperwork completion, communication with HCPs when away from home, and addressing dissatisfaction with care. Examples of using ORA to self-motivate and self-monitor included tracking blood glucose, weight loss, or cholesterol.

> *"when people have got something like that, to lose weight and to watch their cholesterol, I think by having something online, it's something for them to go to and check, I don't know, daily, weekly, monthly, whatever they want to do, it just gives them a bit more motivation." (P45, male, aged 41 years)*

Interactive capabilities

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Participants reported finding interactive capabilities of ORA systems useful, especially appointment booking, and ordering prescriptions, but found difficulties with basic interactive functions (e.g. login, printing, searching, downloading information). Some valued being able to book appointments online as an alternative to having to explain reasons for appointment requests to receptionists.

> "I rang the surgery, they said, no, there's nothing for two weeks, or whatever. My sister, who's on it, said, use your patient access, because I'd forgotten. I went on and I was able to book an appointment for the next day". (P32, female, aged 57 years)

Participants reported that ORA could make their role as a carer easier by acting as an aide memoire, giving them more control over medications, reminding parents when their child's immunizations were due, or helping complete benefit applications.

> "I help her to fill in her PIP forms and things like that, and it was an absolute nightmare back and forward, back and forward to the GP … if I could have accessed that on her behalf, it would have been a million times easier" (P52, female, aged 44 years)

Suggested improvements to interactive capabilities included more advanced login methods, a triage feature for online appointment booking, medication reminders, and pharmacy stock checks.

> "I'd much prefer that it loaded up on the app that I need whatever antibiotic as soon as I leave the GP, tap it, it says it's in stock at your specific pharmacy. Amazon have, like, 'there's 15 of these in stock' " (P45, male, aged 41 years)

3. Consequences of online access to records

Patient safety

Participants noted that ORA could improve safety by reducing the likelihood that test results would go unnoticed, or enabling them to spot errors in their record.

> "I had to correct, both on the dates and on the data… because if, for example, I get

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taken to hospital and the hospital can access this and they're going to make decisions based on the evidence that they see in front of them … that might affect my life" (P19, male, aged 76 years)

Others noted however that ORA could negatively impact patient safety by encouraging unreliable self-diagnosis, self-medication, or discouraging HCPs from documenting concerns regarding issues such as mental health or abuse, for fear of upsetting patients.

Communication between HCPs

Concerns such as those raised above could impact negatively on communication between HCPs, and there was some discussion about how this could be addressed.

"you wouldn't want to be doubling any doctor's workload in terms of writing an account that's for the patient and writing an account that's for another professional to read, but I'm not sure that one could always serve both" (P22, female, aged 44 years)

It was however felt that ORA could aid communication between HCPs indirectly by giving patients the ability to show HCPs not usually involved in their care their medical notes whilst away from home. Participants suggested communication between HCPs could be improved further by greater integration of primary, secondary, and community health care records.

The HCP-patient relationship

Participants felt ORA could foster a culture of openness, improve communication, and increase accountability.

"your MP, or whatever, they're all accountable, we can look up what they're saying and all that, why not my GP?" (P30, male, aged 48 years)

Participants also noted that having access to hospital letters could improve communication by empowering them to question conflicting advice. Greater transparency from ORA could also raise standards of care by enabling holding HCPs to account.

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"it would improve standards that way because doctors would know what they write is there for everyone to see" (P36, female, aged 46 years)

Some worried that ORA could replace face to face contact with HCPs or increase social isolation.

"don't do it by computer, just go down yourself and order it and make a day out of it. Take your friend, go to the bar, have a snack or a cup of coffee … it keeps you out of the house" (P15, male, aged 77 years)

Test results

A common concern was that test results which may previously have been cautiously explained during consultations could be viewed by patients before there was a chance to discuss them.

"if you get a really bad test result sometimes the doctor can kind of reassure you about ways that they can help you, but if you just find out about it you might just completely worry about it" (P53, male, aged 21 years)

Proposed solutions included entries about results being written in plain English or for patients to have 'write' access to their notes to instigate dialogue, with some participants suggesting enabling patients to share information from wearables or the 'internet of things'. Solutions proposed to address the issue of test results causing anxiety included systems ensuring patients could not see results until they had first been viewed by a clinician, although some were conflicted.

"I'd want to see them straight away … I don't necessarily think that would be a beneficial thing to do though, I think obviously once the doctor's interpreted it, they can sort of let you know what you need to know in a way that you need to know it. I mean, I get anxious around health things anyway" (P50, female, aged 40 years)

One participant proposed a built-in feature to enable identification of individuals for whom ORA may be causing anxiety.

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> *"Because that would be a failsafe thing if you had someone who was constantly and obviously very anxiously accessing their records, that should flag up that that person needs to have a conversation" (P23, female, aged 60 years)*

Health inequalities

Participants noted how ORA could lessen health inequalities. For example, one wheelchair user noted that online access could improve their access to healthcare, others living in rural areas noted similar benefits.

> *"there's no point driving ten miles, to ask one question, when you could do it online in two minutes". (P45, male, aged 41 years)*

There were significant concerns however that ORA could exacerbate health inequalities. Digital literacy was a particular concern, especially as surgery staff were not always able to help. In addition, those who are reliant on using computers and free WiFi in public spaces may be disadvantaged in terms of privacy. Concerns were also voiced regarding general literacy, not speaking English as a first language, and identification required to register.

Participants suggested addressing inequalities in digital literacy by providing training, either at GP surgeries or community locations, as well as access to resources.

> *"..have a list of places that people can go for help… or even have an open day or an hour, just for people to take that information when they register, and then maybe someone there to show them how to use it". (P32, female, aged 57 years)*

Literacy and language issues could be partially mitigated by incorporating a 'medical dictionary' and translate function, or providing training for GPs on writing consultation notes. Participants also suggested that problems related to registration could be addressed by simplifying the paperwork and extending the types of identification accepted.

Confidentiality and security

Whilst many participants felt that the security of ORA was adequate, others expressed serious concerns. Those with the strongest objections to ORA tended to be older, have less

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confidence in using the internet, and felt older people might be more likely to be targeted by fraudsters. Concerns were also raised about unwanted access due to the coercion of an abusive partner or employer.

> *"if someone phones in sick for work and their employer for whatever reason challenges them … Is the employer going to then, sort of, force this person to basically hand over their phone and [say] 'I'll just have a look, make sure you've been to the doctor'?…" (P51, male, aged 40 years)*

A number of participants also highlighted anxieties about data sharing with private companies, or that security can be affected by simple user oversights, such as not password protecting a mobile phone. Most participants indicated that measures such as two-factor authentication or biometric access would make them feel more confident. Others stated that they would like control over who can access which parts of their record. This included proxy access (permitted access by a relative or carer) and the ability to revoke such access easily in the future.

> *"would I want my immediate family reading what I've said? … I think it might have to be potentially an option within the system to say that that individual can have access to certain aspects of my records but not the entire thing" (P37, female, aged 49 years)*

Impact on resource allocation

Participants generally felt ORA could reduce the need to travel to appointments or spend time in long telephone queues.

> *"I was on the phone for ages, I couldn't get through…I needed my blood results because I was going to an appointment, so I ended up jumping in the car, driving down and saying, can you please...and they printed it out and gave it to me. So yeah, I could have just literally tabbed on and printed it out myself" (P37, female, aged 41 years)*

> *"There might be issues where it's a simple question to a GP that could just be a text*

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and a text back, job done, rather than setting up a whole appointment" (P44, male, aged 49 years)

There were mixed views regarding the impact of ORA on primary care staff resource allocation. Participants suggested it could reduce demand for GP appointments and reduce practice workload. It was also felt ORA might prompt preventative action from patients which could further reduce pressures on primary care. Despite these positives, there were concerns that ORA could increase HCP workload in a variety of ways such as prompting patients to call practices to discuss test results they had seen but not understood, or GPs needing to spend more time documenting consultations.

4. Inevitability of shift towards online services

Whilst there was some resistance to the move towards online services, especially amongst some of the older participants and those from ethnic minority groups, there was an acknowledgement that much personal data is already held online.

"Our records are online anyway, aren't they, really? Everything's online already …so it's just really us being able to get access to it really" (P40, female, aged 60 years)

Participants compared ORA with previous transformational societal changes, such as: the postal system, aviation, and online banking.

"Yeah, I do online banking. You're not forced to do it these days, but that seems to be the way that everything's going, so you've kind of got to roll with it" (P45, male, aged 41 years)

Several participants noted generational differences in terms of acceptance of ORA, and one discussion focussed on how those who resist services such as ORA tend to be older, and are gradually being replaced by more technologically-savvy generations.

"It will become much more universal that everybody knows that you have to access the internet in order to live a normal life, and the older people who still won't look at it won't be here forever, probably." (P9, male, aged 76 years)

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DISCUSSION

Participants saw both benefits and drawbacks to ORA, but a move towards more online health services was considered inevitable. The results of this study highlight a range of ways in which ORA can be promoted to those who lack awareness of, or motivation to use, this service. It has shown how systems could be improved to better meet the needs and preferences of patients, address their concerns about privacy and security, increase patient involvement in care, strengthen relationships between patients and care providers, and reduce risks to patient safety. Additionally, whilst ORA has the potential to exacerbate health inequalities, it may also decrease them, especially where training or facilities are made available, and consultation summaries and interpretations of test results are written in plain English.

Comparison with existing literature

Our findings resonate with previous qualitative work in this area.[11, 12, 13] Concerns regarding security and trustworthiness, and ORA acting as a communication aid were discussed in our *consequences* theme. ORA providing greater interactivity, and serving educational and practical functions were topics discussed in our *capabilities* theme. Our study has updated this knowledge and cast further light on what patients want from ORA in primary care. Unlike previous work in this area, which was concerned with evaluating pre-existing [11, 13] or tertiary care systems for specific conditions,[12] our study examined people's views regarding ORA in primary care, and what features and functions patients would like to see in such systems in the future.

This study contains a number of novel findings regarding the needs and expectations of patients and carers with respect to ORA. Many people are still unaware this service exists [21] and it needs to be better promoted if the UK government's vision is to be realised. It has also revealed an understandable desire for greater consistency across time and between users in terms of what people can actually see with ORA. Interesting suggestions regarding the capabilities of ORA systems include incorporating the ability for patients to check if their pharmacy is out of stock of their medication; this issue has become particularly troublesome for primary care patients in recent years.[22] Our findings regarding patients' wishes to

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integrate online records systems with wearable devices are also novel, as are suggestions to provide a greater degree of control over who can access one's record and the ability to set varying levels of access to different third parties. Such features are commonplace on social media platforms such as Facebook. The suggestion of allowing patients to request different modes of appointment (i.e. telephone, video, face to face) is especially interesting given recent changes to the way GPs are working in light of the coronavirus pandemic.

Strengths and limitations

The strengths of this study include the diversity of the sample in terms of age, socioeconomic status and ethnicity, and the inclusion of participants from seldom heard communities. Such individuals are more likely to be affected by issues such as health inequalities and the 'digital divide'.[23]

Limitations to this study include the fact that the researchers' backgrounds may have influenced the dynamic of the interviews and subsequent findings, but consideration of reflexivity, and discussions with the rest of the research team helped to avoid an overly narrow interpretation of the findings. Also, the study examined the views of participants regarding ORA, rather than making observations of their actual behaviour. We took the commonly adopted critical realist perspective, which holds that some degree of truth can be ascertained through the examination of qualitative data, whilst acknowledging that this is nuanced by human interpretation.[19] Future feasibility work will cast more light upon the impact of incorporating participants' suggested improvements into ORA systems.

Implications for policy, practice and research

If we are to fulfil the UK Government's expectations that all patients should have online access to their full primary care record, [24] we will need to ensure that online access is better promoted. As more patients start using ORA, we will also need to provide better support for patients and carers to get the most out of this service as well as additional training for practice staff.

Although patients have had the statutory right to access to their medical records since 1991,[25] HCPs now need to be even more mindful of the fact that their entries may be viewed by patients. GPs and other HCPs will need to adapt the way they write in the record

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so that it can be easily understood by patients, as not doing so may result in an increased workload due to more patient enquires. HCPs will also need to ensure that systems are in place to communicate concerns regarding sensitive issues such as safeguarding or domestic abuse to other HCPs without compromising the HCP-patient relationship or putting patients at risk.

If we are to meet patient expectations regarding ORA, we need to go beyond simply enabling patients to view information. We should aim to collaborate with patients, carers, clinicians, the IT industry, behaviour change experts, policymakers, and the NHS to shape the online record into an interactive tool than can motivate, educate, and provide the opportunity for patients to become more engaged in their own healthcare. This will provide a new set of challenges, such as developing accreditation to ensure that the data provided by wearables is accurate and reliable. We also need to be mindful that the shift towards more provision of services via online systems does not exacerbate health inequalities.

Footnotes

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Appendix 1

What do patients and carers want from online access to GP (Primary Care) records?

Participant Information Sheet (PIS)

You are being invited to take part in a research study to find out more about what patients and carers want from online access to GP (Primary Care) records. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

➢ **Who will conduct the research?**

Dr Brian McMillan, Prof Caroline Sanders and Dr Gail Davidge (Division of Population Health, Health Services Research and Primary Care, School of Health Sciences, University of Manchester) in collaboration with Dr Helen Atherton (Warwick Medical School, University of Warwick) and Dr Freda Mold (School of Health Sciences, University of Surrey).

➢ **What is the purpose of the research?**

'Online access' refers to patients and their carers being able to access their GP record (or the record of the person they care for) online. Research shows benefits of online access to records, for example, people feel more in control and more able to communicate with healthcare staff. The down sides include some professionals not being keen on the idea, people worrying about how secure this is, or not always understanding what is in their record.

Research has mainly looked at the pros and cons of online access, or at how people look at their record. More research is needed to find out how to design patient records to support people to stay healthier for longer. For people to get the most out of being able to see their health record (or the record of the person they care for) online, we need to understand more about what people actually want from online access to records.

The study asks: What do people want from online access to their GP record (or the record of the person they care for), what would they like to be able to do with this, and what help might they need?

The study aims to talk to people to find out their views about online access. This will help to design future online access services.

You have been chosen because you belong to one of the three groups of people we are interested in: 1) healthy people aged 40-74 years, 2) people aged over 16 years with more than one long term

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health condition, and 3) their carers. We chose these three groups as there is evidence they could benefit especially from online access to records. We are aiming to recruit a minimum of 50 participants in total.

➤ **Will the outcomes of the research be published?**

We will make the findings available to health care professionals, researchers, government representatives, and software companies who can all help shape and improve future online records access services. We will also publish the results in scientific journals and inform patient groups about the results. We will send you a summary of our findings if you request this.

➤ **Who has reviewed the research project?**

The project has been reviewed by the North West - Greater Manchester NHS Research Ethics Committee (reference number: 19/NW/0293).

➤ **Who is funding the research project?**

This study has been funded by the National Institute for Health Research School for Primary Care Research (SPCR-2014-10043: Grant reference number 429).

What would my involvement be?

➤ **What would I be asked to do if I took part?**

You will be invited to take part in either a focus group or a one-to-one interview to discuss your views about online access to GP records (a focus group is a group of around 6 people who sit in the same room and have a discussion guided by a researcher). Focus groups and interviews will last up to one hour and take place at times and in locations that are convenient to those taking part. We will audio-record these discussions so that we can fully consider and review all that is said. A University of Manchester approved supplier will type up the recordings before we analyse them in our research.

We recognise that some participants may feel upset if talking about difficult experiences. The researcher will be sensitive to this and will encourage people to take a break or possibly withdraw from the activity if the discussion becomes upsetting.

There are no immediate direct benefits to taking part, but you will have the opportunity to participate in research that aims to contribute to the improvement of services providing online access to GP records, which may personally benefit you in the future.

➤ **Will I be compensated for taking part?**

To say thanks for taking part in this study we will give you a £15 shopping voucher.

IRAS project ID 256065   **What do patients want from online access to their GP record?**
Appendix 5: Participant Information Sheet   **Version 4 03 July2019**

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➢ **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you wish to take part please complete and return the enclosed consent form in the envelope provided. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further. We plan to audio record the interviews and focus group but you are free to decline to be recorded. Participants should be comfortable with the recording process at all times and they are free to stop the recording at any time.

Data Protection and Confidentiality

➢ **What information will you collect about me?**

In order to participate in this research project we will need to collect information that could identify you, called "personal identifiable information". Specifically we will need to collect:

- your name
- your contact details (telephone number, address, or e-mail address)
- your postcode
- your age
- your gender
- your ethnic group
- your level of education and occupation
- if you have any medical conditions (you don't have to tell us what they are)
- if you are a carer

The audio recordings will record voice only and will be obtained during focus groups and interviews.

➢ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

➢ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research (http://documents.manchester.ac.uk/display.aspx?DocID=37095).

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➢ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way.

Only the study team at The University of Manchester will have access to your personal information, but they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. Only the research team at the University of Manchester will have access to the key that links this ID number to your personal information. Your consent form and contact details will be retained in a locked filing cabinet until the end of the study so that we can send you a copy of the findings.

Potential disclosures:

If, during the study, we have concerns about your safety or the safety of others, we will ask you to discuss these with your GP. If, during the study, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities. Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

Audio recordings will be held on a University of Manchester approved encrypted recording device that can only be accessed using a PIN number until the researcher returns to the University (this will normally be on the same day). Audio recordings will be transferred from the recording device to secure University of Manchester Storage as soon as possible, checked and then deleted form the recording device. Recordings will be transcribed (typed up) in a secure environment by a University of Manchester approved transcription service. Any information that could identify you or anyone else you mention will be removed from transcriptions (such as names or reference to unusual conditions). Audio recordings will be destroyed as soon as possible after transcripts have been checked for accuracy.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

➢ **Contact details for complaints**

If you have a complaint that you wish to direct to members of the research team, please contact:

DR BRIAN MCMILLAN, e-mail: BRIAN.MCMILLAN@MANCHESTER.AC.UK, TEL: 0161 2757662

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If we are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 2674 or 275 2046 or by email to research.complaints@manchester.ac.uk.

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Governance and Integrity Officer, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information (https://ico.org.uk/make-a-complaint/) Tel: 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact:

DR BRIAN MCMILLAN
CENTRE FOR PRIMARY CARE AND HEALTH SERVICES RESEARCH
UNIVERSITY OF MANCHESTER
WILLIAMSON BUILDING
OXFORD ROAD
MANCHESTER
M13 9PL

TEL: 0161 2757662
EMAIL: BRIAN.MCMILLAN@MANCHESTER.AC.UK

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Appendix 2

Topic Guide

Research aims:

Primary objective: To explore what two groups of primary care patients (those eligible for the NHS Health Check and those with multimorbidities), and their carers want from online access to their electronic primary care health record (GP record).

Secondary Objective: To examine how two groups of primary care patients (those eligible for the NHS Health Check and those with multimorbidities) and their carers would like to interact with their online primary care health record, and what support they may need

Introduction:
- – Welcome
- – Provide an outline of the study, including a definition of 'online access' – intended to stimulate conversation
- – Recap details of participation
    - – Voluntary (can withdraw any time)
    - – Confidential
    - – Audio recording of focus group and data protection (but will be anonymised)
    - – Length of meeting – up to one hour

Ground rules:

We'd like you to do most of the talking

- – We may ask your views if we've not heard from you in a while (but don't feel under pressure to say something if you don't want to)
- – No need to discuss anything that makes you feel uncomfortable
- – The importance of hearing everyone's views (try not to talk over each other, difficult to tell who's talking when listening back to the recording)
- – There are no right or wrong answers (i.e. important to hear a full range of views)
- – We should show each other respect even if we disagree
- – What's shared in this room stays in this room (we will summarise findings without revealing anything that could identify an individual or anyone they discuss)
- – Any questions?

Participant background:
- • Ask each participant to introduce themselves
    - o Consider only using their first name

Awareness of online access:

Ask for a show of hands – who has heard of online access?

- o Those who have - where did you hear about it?
    - ▪ What were your thoughts when you heard about it?

Experience of online access:
- Ask for a show of hands - has anyone used online access at their GP practice?
  - Those who have
    - How easy was it to sign up?
    - What sort of things have you used it for?
    - How easy is it to use?

General views regarding online access (make sure to include those who have not heard of or used online access before):
- What do you think about the idea of online access generally?
  - Why?
  - What do you think are the pros (good points) and cons (bad points) about online access?
    - The benefits and disadvantages raised here should then be explored in greater depth

Needs and expectations regarding online access
This should flow from the previous conversations

- With regards to accessing your (/the person you care for) GP record online, <u>what</u> would you like to be able to do?
  - Use alternative phrasings if this does not stimulate conversation such as;
    - 'What features would you like to see in your (of the person you care for) online record?'

- With regards to accessing your (/the person you care for) GP record online, <u>how</u> would you like to be able to do it?
  - Use additional prompts if this does not stimulate conversation such as;
    - In the early days, some GP surgeries had kiosks installed in their waiting rooms where people could log in and see their record. What other ways you can think of that might be useful (e.g., equipment/space/support)?

- With regards to accessing your (/the person you care for) GP record online, <u>what sort</u> of support would you like?
  - Use additional prompts if this does not stimulate conversation such as;
    - Some people (/carers) might find it difficult to use online services; can you think of the sorts of things that might help them?

The future of online access
- With regards to access your (/the person you care for) GP record online, what sort of things do you imagine you might be able to do in the future?
  - (For possibilities raised) Do you think this is a good thing or a bad thing?
  - (For possibilities raised) Are there better ways this could be done?

Final thoughts
- Is there anything that anyone would like to add to the discussion?

Thank you for giving your time to discuss these issues

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	5
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The	5

rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.

Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	6
Context	#7	Setting / site and salient contextual factors; rationale	5
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	5
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	17
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	6
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	6
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	6
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	6
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	6

Results/findings

Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	6
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	15

Discussion

| Intergration with prior work, implications, transferability and contribution(s) to the field | #18 | Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field | 15 |
| Limitations | #19 | Trustworthiness and limitations of findings | 16 |

Other

| Conflicts of interest | #20 | Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed | n/a |
| Funding | #21 | Sources of funding and other support; role of funders in data collection, interpretation and reporting | 17 |

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BMJ Open

A qualitative exploration of patients' experiences, needs, and expectations regarding online access to their primary care record

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A qualitative exploration of patients' experiences, needs, and expectations regarding online access to their primary care record

Brian McMillan*[1], Gail Davidge[1], Lindsey Brown[1], Moira Lyons[1], Helen Atherton[2], Rebecca Goulding[1], Freda Mold[3], Rebecca Morris[1], Caroline Sanders[1]

1. Centre for Primary Care and Health Services Research, University of Manchester, UK

2. Warwick Medical School, University of Warwick, UK

3. School of Health Sciences, University of Surrey, UK

*Corresponding author: Dr Brian McMillan, Centre for Primary Care and Health Services Research, Suite 3, Floor 6, Williamson Building, Oxford Road, University of Manchester, England, M13 9PL. E-mail: brian.mcmillan@manchester.ac.uk Tel: 0161 2757656, Fax: 0161 2757600

Word count: 4081

ABSTRACT

Objectives: Primary care records have traditionally served the needs and demands of clinicians rather than those of the patient. In England, General Practices must promote and offer registered patients online access to their primary care record, and research has shown benefits to both patients and clinicians of doing so. Despite this, we know little about patients' needs and expectations regarding online access to their record. This study explored what patients and carers want from online access to their electronic primary care health record, their experiences of using it, how they would like to interact with their record, and what support they may need.

Design: Focus groups and semi-structured interviews using purposive sampling to achieve a good sociodemographic spread. Interviews were digitally audio-recorded, transcribed and coded using an established thematic approach.

Setting: Focus groups and interviews were conducted in community settings in the UK.

Participants: Fifty four individuals who were either eligible for the NHS Health Check, living with more than one long-term condition, or caring for someone else.

Results: Participants views regarding online access were categorised into 4 main themes: awareness, capabilities, consequences, and inevitability. Participants felt online access should be better promoted, and suggested a number of additional functions, such as better integration with other parts of the healthcare system. It was felt that online access could improve quality of care (e.g. through increased transparency) but also have potential negative consequences (e.g. by replacing face to face contact). A move towards more online records access was considered inevitable, but participants noted a need for additional support and training in using the online record, especially to ensure that health inequalities are not exacerbated.

Conclusions: Discussions with patients and carers about their views of accessing online records have provided useful insights into future directions and potential improvements for this service.

Strengths and limitations of this study

- This is the first UK based study to explore the experiences, needs, and expectations of patients regarding online access to their primary care record, and to discuss the implications for the development of these services.

- Purposive sampling was employed to ensure a good sociodemographic mix, with individuals from urban and rural areas, and varying degrees of digital and health literacy.

- Patient and public participation in the research ensured it remained patient focussed and included views from seldom-heard groups.

- A mixture of focus groups and one to one interviews enabled exploration of shared experiences and understandings whilst also allowing further probing of minority or controversial opinions and discussion of sensitive issues.

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INTRODUCTION

The GP Contract in England states all patients should have online access to their full primary care record. [1] Whilst this has not been fully implemented, 24% of patients in England have signed up for online records access (ORA)[2] via the NHS App or other NHS-approved service.[3] Systematic reviews examining ORA have identified a number of potential benefits and drawbacks.[4, 5, 6] Patients can use ORA as an aide-mémoire, to help prepare for their next appointment,[7, 8] and report that it saves time by reducing the number of telephone calls and appointments required.[4, 7] ORA can increase patients' feelings of autonomy,[9] enable them to spot and correct medication errors,[4, 6] and positively impacts on clinical measures such as HbA1c.[6] However, clinicians have expressed concerns that ORA could cause unnecessary anxiety, increase complaints, and threaten confidentiality and security. [5] Other concerns relate to: widening health inequalities, risk of coercion, and increased clinician workload.[10]

Research has looked at what patients do with ORA and its impact on patient satisfaction and engagement. However, there has been little research examining what patients *want* from ORA. Overlooking patients' needs and expectations may prevent patient ORA from achieving its full potential. Only three qualitative studies have examined what patients want from ORA,[11, 12, 13] indicating they want it to: 1) be secure and trustworthy, 2) act as a communication aid, 3) be more interactive, 4) serve an educational function, 5) serve practical functions. These studies identified the importance of ORA aiding communication between patients and healthcare professionals (HCPs), other family members, carers, or between HCPs. Patients would like to be able to write into their record,[12, 13] and expressed a desire for decision aids,[11] and lifestyle management with signposting to services.[11, 12] Sought after educational functions included plain English explanations of medical terms,[12, 13] and practical functions including booking appointments,[12] viewing test results,[12, 13] and accessing information needed to complete benefit applications.[12]

Although these qualitative studies have started to identify what patients want from ORA, only one was primary care based and conducted in the UK, and was carried out over 16 years ago examining a significantly different service than is available today.[13] The authors noted that "working in partnership with patients to develop systems is essential to their

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success".[13, p38] To achieve this, we need to ascertain what patients would like from ORA rather than simply asking them to evaluate systems that already exist.

Through our Patient and Public Involvement and Engagement (PPIE) work[14] and previous reviews,[4, 15, 16] we identified three diverse groups likely to have different needs and expectations of ORA: those eligible for the NHS Health Check[17] who value ORA to understand how they might maintain good health[14] and those with multimorbidities and carers, who value it for managing their conditions or the conditions of those they care for.[4] This study therefore aims to explore patients' and carers'

- awareness and experiences of ORA
- views and beliefs regarding ORA
- expressed needs and expectations regarding ORA, including required support.

METHODS

Given the limitations of the existing evidence base in this area, an exploratory qualitative study, informed by grounded theory, was conducted. Data were collected through focus groups and semi-structured interviews in community settings in the UK, followed by an inductive thematic analysis [18].

Sampling and recruitment

A purposive sampling strategy was employed to achieve maximum variability for factors known to impact ORA, such as age, sex, socioeconomic status, and ethnicity.[19] Recruitment methods included utilising the Greater Manchester Clinical Research Network (CRN), approaching community organizations, and snowballing. A participant information leaflet described the study in detail and listed the eligibility criteria (see Appendix 1). Informed written consent was obtained, and focus groups were held until the research team considered that data saturation was approaching,[18] at which point recruitment switched to semi-structured interviews to explore issues raised in greater depth. Participants who were interviewed had not previously participated in the focus groups. Recruitment ceased when no new or discordant themes were identified.

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Data collection methods

A total of 11 focus groups and 9 interviews were conducted. The topic guide (Appendix 2) covered five main areas regarding ORA: awareness; experiences; views; needs and expectations; and perceptions of the future. The focus groups and interviews lasted 30-60 minutes, were digitally audio recorded, and transcribed by a university approved service.

Patient and public involvement

The topic guide was developed following observations of clinical consultations at a practice where patients have full ORA, a patient and public involvement and engagement (PPIE) workshop,[14] and discussions with the Primary Care Research in Manchester Engagement Resource (PRIMER) group, two members of which are co-authors of this paper (LB & ML).

Data analysis

Transcripts were anonymised, imported into QSR NVivo 12,[20] and checked for accuracy. BM and GD independently coded the transcripts, using the thematic analysis approach , which involved six phases; data familiarization; coding; identification of candidate themes; review and revision of themes; definition and naming of themes; analysis and interpretation of patterns across the data.[18] Although the traditional concept of validity is problematic in qualitative research [18], discussions amongst the research team helped identify key issues, verify themes, and ensure consistency of coding. In addition, we sought to enhance dependability of our findings by involving two members of the public (LB, ML) in two half-day workshops during which we refined the themes using Ketso, a toolkit for creative engagement.[21] .

RESULTS

Demographics

A total of 27 women and 27 men aged between 21 and 87 years (mean = 59.0; SD = 15.4) participated from a wide range of socioeconomic backgrounds.[22] We conducted 11 focus groups totalling 36 participants, and 9 individual interviews (see Table 1).

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Themes

Patients' and carers' views of ORA concerned four main themes: *1. Awareness, 2. Capabilities*, *3. Consequences*, and *4. Inevitability*.

1. Awareness of online records access

Less than half the participants were aware of ORA. Those who were reported it had been promoted by their GP surgery or had heard of it by word of mouth. Some felt they had no reason to use ORA, found it easier to find information by other means, or felt accessing

Table 1. Participant demographic characteristics (N=54)

Characteristic	n	%
Self-identify as carer	19	35.2
>1 long-term medical condition	24	44.4
Eligible for NHS Health Check	30	55.6
Aware of ORA	23	42.6
Previously used ORA	10	18.5
Frequency of internet usage		
Frequently	41	75.9
Occasionally	10	18.5
Never	3	5.6
Ethnicity		
White	43	79.6
Asian	4	7.4
Black	7	13.0
Education		
Degree level	12	22.2
Further education	7	13.0
School to 16 years of age	25	46.3
School to ≤ 16 years of age	10	18.5
Occupation		
Retired	19	35.2
Professional	8	14.8
Sales/customer service	4	7.4
Caring/leisure/other	13	24.1
Admin/secretarial	1	1.9
Associate/technical	2	3.7
Self-employed	3	5.6
Not working	4	7.4
Index of multiple deprivation [22]		
Deciles 1-3 (most deprived)	16	29.6
Deciles 4-7	17	31.5

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Deciles 8-10 (least deprived)	21	38.9
Rural-urban classification [23]		
Urban	32	59.2
Suburban	9	16.7
Rural	13	24.1

medical records was best left to HCPs. Some expressed annoyance that they had not been informed about ORA, whilst others stated that learning about the service had not made them any more likely to use it. Participants felt ORA was poorly advertised, and suggested promoting it via media advertisements, posters in surgeries, and during GP consultations.

2. Capabilities of online records access

Access to information

Participants reported ORA enabled them to view: test results, medication lists, allergies, immunizations, appointment details, problem lists, secondary care letters, and consultation notes, but expressed dissatisfaction with the content, detail, and presentation of the information. Suggested improvements included: direct links to sources of support, more information about the HCPs providing care, better integration with other services, full retrospective access, easier and more consistent access to information, use of plain English, and links to trusted sources of information. Several wished to access all their health and care records via one fully integrated system.

Enabling active involvement

Participants who had used ORA noted that it enabled them to be more actively involved in their own health and care, and those who had not felt it could, by facilitating: self-monitoring, self-education (e.g. looking up meanings of terms seen in record), self-reassurance, appointment preparation, use of the record as an aide-mémoire or motivational tool, paperwork completion, communication with HCPs when away from home, and addressing dissatisfaction with care. Examples of using ORA to self-motivate and self-monitor included tracking blood glucose, weight loss, or cholesterol.

> *"when people have got something like that, to lose weight and to watch their*

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cholesterol, I think by having something online, it's something for them to go to and check, I don't know, daily, weekly, monthly, whatever they want to do, it just gives them a bit more motivation." (P45)

Interactive capabilities

Participants reported finding interactive capabilities of ORA systems useful, especially appointment booking, and ordering prescriptions, but found difficulties with basic interactive functions (e.g. login, printing, searching, downloading information). Some valued being able to book appointments online as an alternative to having to explain reasons for appointment requests to receptionists.

"I rang the surgery, they said, no, there's nothing for two weeks, or whatever. My sister, who's on it, said, use your patient access, because I'd forgotten. I went on and I was able to book an appointment for the next day". (P32)

Participants reported that ORA could make their role as a carer easier by acting as an aide memoire, giving them more control over medications, reminding parents when their child's immunizations were due, or helping complete benefit applications.

"I help her to fill in her PIP forms and things like that, and it was an absolute nightmare back and forward, back and forward to the GP … if I could have accessed that on her behalf, it would have been a million times easier" (P52)

Suggested improvements to interactive capabilities included more advanced login methods, a triage feature for online appointment booking, medication reminders, and pharmacy stock checks.

"I'd much prefer that it loaded up on the app that I need whatever antibiotic as soon as I leave the GP, tap it, it says it's in stock at your specific pharmacy. Amazon have, like, 'there's 15 of these in stock' " (P45)

3. Consequences of online access to records

Patient safety

Participants noted that ORA could improve safety by reducing the likelihood that test results would go unnoticed, or enabling them to spot errors in their record.

> *"I had to correct, both on the dates and on the data… because if, for example, I get taken to hospital and the hospital can access this and they're going to make decisions based on the evidence that they see in front of them … that might affect my life" (P19)*

Others noted however that ORA could negatively impact patient safety by encouraging unreliable self-diagnosis, self-medication, or discouraging HCPs from documenting concerns regarding issues such as mental health or abuse, for fear of upsetting patients.

Communication between HCPs

Concerns such as those raised above could impact negatively on communication between HCPs, and there was some discussion about how this could be addressed.

> *"you wouldn't want to be doubling any doctor's workload in terms of writing an account that's for the patient and writing an account that's for another professional to read, but I'm not sure that one could always serve both" (P22)*

It was however felt that ORA could aid communication between HCPs indirectly by giving patients the ability to show HCPs not usually involved in their care their medical notes whilst away from home. Participants suggested communication between HCPs could be improved further by greater integration of primary, secondary, and community health care records.

The HCP-patient relationship

Participants felt ORA could foster a culture of openness, improve communication, and increase accountability.

> *"your MP [Member of Parliament], or whatever, they're all accountable, we can look up what they're saying and all that, why not my GP?" (P30)*

Participants also noted that having access to hospital letters could improve communication

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by empowering them to question conflicting advice. Greater transparency from ORA could also raise standards of care by enabling holding HCPs to account.

> *"it would improve standards that way because doctors would know what they write is there for everyone to see" (P36)*

Some worried that ORA could replace face to face contact with HCPs or increase social isolation.

> *"don't do it by computer, just go down yourself and order it and make a day out of it. Take your friend, go to the bar, have a snack or a cup of coffee … it keeps you out of the house" (P15)*

Test results

A common concern was that test results which may previously have been cautiously explained during consultations could be viewed by patients before there was a chance to discuss them.

> *"if you get a really bad test result sometimes the doctor can kind of reassure you about ways that they can help you, but if you just find out about it you might just completely worry about it" (P53)*

Proposed solutions included entries about results being written in plain English or for patients to have 'write' access to their notes to instigate dialogue, with some participants suggesting enabling patients to share information from wearables or the 'internet of things'. Solutions proposed to address the issue of test results causing anxiety included systems ensuring patients could not see results until they had first been viewed by a clinician, although some were conflicted.

> *"I'd want to see them straight away … I don't necessarily think that would be a beneficial thing to do though, I think obviously once the doctor's interpreted it, they can sort of let you know what you need to know in a way that you need to know it. I mean, I get anxious around health things anyway" (P50)*

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One participant proposed a built-in feature to enable identification of individuals for whom ORA may be causing anxiety.

> *"Because that would be a failsafe thing if you had someone who was constantly and obviously very anxiously accessing their records, that should flag up that that person needs to have a conversation" (P23)*

Health inequalities

Participants noted how ORA could lessen health inequalities. For example, one wheelchair user noted that online access could improve their access to healthcare, others living in rural areas noted similar benefits.

> *"there's no point driving ten miles, to ask one question, when you could do it online in two minutes". (P45)*

There were significant concerns however that ORA could exacerbate health inequalities. Digital literacy was a particular concern, especially as surgery staff were not always able to help. In addition, those who are reliant on using computers and free WiFi in public spaces may be disadvantaged in terms of privacy. Concerns were also voiced regarding general literacy, not speaking English as a first language, and identification required to register.

Participants suggested addressing inequalities in digital literacy by providing training, either at GP surgeries or community locations, as well as access to resources.

> *"..have a list of places that people can go for help... or even have an open day or an hour, just for people to take that information when they register, and then maybe someone there to show them how to use it". (P32)*

Literacy and language issues could be partially mitigated by incorporating a 'medical dictionary' and translate function, or providing training for GPs on writing consultation notes. Participants also suggested that problems related to registration could be addressed by simplifying the paperwork and extending the types of identification accepted.

Confidentiality and security

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Whilst many participants felt that the security of ORA was adequate, others expressed serious concerns. Those with the strongest objections to ORA tended to be older, have less confidence in using the internet, and felt older people might be more likely to be targeted by fraudsters. Concerns were also raised about unwanted access due to the coercion of an abusive partner or employer.

> *"if someone phones in sick for work and their employer for whatever reason challenges them … Is the employer going to then, sort of, force this person to basically hand over their phone and [say] 'I'll just have a look, make sure you've been to the doctor'?…" (P51)*

A number of participants also highlighted anxieties about data sharing with private companies, or that security can be affected by simple user oversights, such as not password protecting a mobile phone. Most participants indicated that measures such as two-factor authentication or biometric access would make them feel more confident. Others stated that they would like control over who can access which parts of their record. This included proxy access (permitted access by a relative or carer) and the ability to revoke such access easily in the future.

> *"would I want my immediate family reading what I've said? … I think it might have to be potentially an option within the system to say that that individual can have access to certain aspects of my records but not the entire thing" (P37)*

Impact on resource allocation

Participants generally felt ORA could reduce the need to travel to appointments or spend time in long telephone queues.

> *"I was on the phone for ages, I couldn't get through…I needed my blood results because I was going to an appointment, so I ended up jumping in the car, driving down and saying, can you please...and they printed it out and gave it to me. So yeah, I could have just literally tabbed on and printed it out myself" (P37)*

> *"There might be issues where it's a simple question to a GP that could just be a text*

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and a text back, job done, rather than setting up a whole appointment" (P44)

There were mixed views regarding the impact of ORA on primary care staff resource allocation. Participants suggested it could reduce demand for GP appointments and reduce practice workload. It was also felt ORA might prompt preventative action from patients which could further reduce pressures on primary care. Despite these positives, there were concerns that ORA could increase HCP workload in a variety of ways such as prompting patients to call practices to discuss test results they had seen but not understood, or GPs needing to spend more time documenting consultations.

4. Inevitability of shift towards online services

Whilst there was some resistance to the move towards online services, especially amongst some of the older participants and those from ethnic minority groups, there was an acknowledgement that much personal data is already held online.

> *"Our records are online anyway, aren't they, really? Everything's online already …so it's just really us being able to get access to it really" (P40)*

Participants compared ORA with previous transformational societal changes, such as: the postal system, aviation, and online banking.

> *"Yeah, I do online banking. You're not forced to do it these days, but that seems to be the way that everything's going, so you've kind of got to roll with it" (P45)*

Several participants noted generational differences in terms of acceptance of ORA, and one discussion focussed on how those who resist services such as ORA tend to be older, and are gradually being replaced by more technologically-savvy generations.

> *"It will become much more universal that everybody knows that you have to access the internet in order to live a normal life, and the older people who still won't look at it won't be here forever, probably." (P9)*

DISCUSSION

Participants saw both benefits and drawbacks to ORA, but a move towards more online health services was considered inevitable. The results of this study highlight a range of ways in which ORA can be promoted to those who lack awareness of, or motivation to use, this service. It has shown how systems could be improved to better meet the needs and preferences of patients, address their concerns about privacy and security, increase patient involvement in care, strengthen relationships between patients and care providers, and reduce risks to patient safety. Additionally, whilst ORA has the potential to exacerbate health inequalities, it may also decrease them, especially where training or facilities are made available, and consultation summaries and interpretations of test results are written in plain English.

Comparison with existing literature

Our findings resonate with previous qualitative work in this area.[11, 12, 13] Concerns regarding security and trustworthiness, and ORA acting as a communication aid were discussed in our *consequences* theme. ORA providing greater interactivity, and serving educational and practical functions were topics discussed in our *capabilities* theme. In line with previous studies,[12, 13] instant access to test results was listed as both a benefit (e.g. in terms of convenience) and a drawback (e.g. the potential to cause unnecessary anxiety), prompting suggestions for improvement such as plain English definitions or pre-screening of results by clinicians. Our study has updated this knowledge and cast further light on what patients want from ORA in primary care. Unlike previous work in this area, which was concerned with evaluating pre-existing [11, 13] or tertiary care systems for specific conditions,[12] our study examined people's views regarding ORA in primary care, and what features and functions patients would like to see in such systems in the future. This work compliments a recent systematic review in this area demonstrating the clinical benefit of online access [6] by providing in-depth insights into how we might further increase patient engagement.

This study contains a number of novel findings regarding the needs and expectations of patients and carers with respect to ORA. Many people are still unaware this service exists [24] and it needs to be better promoted if the UK government's vision is to be realised. It has also revealed an understandable desire for greater consistency across time and between

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users in terms of what people can actually see with ORA. Interesting suggestions regarding the capabilities of ORA systems include incorporating the ability for patients to check if their pharmacy is out of stock of their medication; this issue has become particularly troublesome for primary care patients in recent years.[25] Our findings regarding patients' wishes to integrate online records systems with wearable devices are also novel, as are suggestions to provide a greater degree of control over who can access one's record and the ability to set varying levels of access to different third parties. Such features are commonplace on social media platforms such as Facebook. The suggestion of allowing patients to request different modes of appointment (i.e. telephone, video, face to face) is especially interesting given recent changes to the way GPs are working in light of the coronavirus pandemic.

Strengths and limitations

The strengths of this study include the diversity of the sample in terms of age, socioeconomic status and ethnicity, and the inclusion of participants from seldom heard communities. Such individuals are more likely to be affected by issues such as health inequalities and the 'digital divide'.[26]

Limitations to this study include the fact that the researchers' backgrounds may have influenced the dynamic of the interviews and subsequent findings, but consideration of reflexivity, and discussions with the rest of the research team helped to avoid an overly narrow interpretation of the findings. Also, the study examined the views of participants regarding ORA, rather than making observations of their actual behaviour. We took the commonly adopted critical realist perspective, which holds that some degree of truth can be ascertained through the examination of qualitative data, whilst acknowledging that this is nuanced by human interpretation.[18] Future feasibility work will cast more light upon the impact of incorporating participants' suggested improvements into ORA systems. Future quantitative research studies could also further explore differences in views and behaviour with respect to online records access between different socio-demographic groups.

Implications for policy, practice and research

If we are to fulfil the UK Government's expectations that all patients should have online access to their full primary care record, [27] we will need to ensure that online access is

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better promoted. As more patients start using ORA, we will also need to provide better support for patients and carers to get the most out of this service as well as additional training for practice staff.

Although patients have had the statutory right to access to their medical records since 1991,[28] HCPs now need to be even more mindful of the fact that their entries may be viewed by patients. GPs and other HCPs will need to adapt the way they write in the record so that it can be easily understood by patients, as not doing so may result in an increased workload due to more patient enquires. HCPs will also need to ensure that systems are in place to communicate concerns regarding sensitive issues such as safeguarding or domestic abuse to other HCPs without compromising the HCP-patient relationship or putting patients at risk.

If we are to meet patient expectations regarding ORA, we need to go beyond simply enabling patients to view information. We should aim to collaborate with patients, carers, clinicians, the IT industry, behaviour change experts, policymakers, and the NHS to shape the online record into an interactive tool than can motivate, educate, and provide the opportunity for patients to become more engaged in their own healthcare. This will provide a new set of challenges, such as developing accreditation to ensure that the data provided by wearables is accurate and reliable. We also need to be mindful that the shift towards more provision of services via online systems does not exacerbate health inequalities.

Footnotes

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Competing interests: None declared

Ethics approval: NHS Health Research Authority Approval was applied for through the IRAS online form (IRAS Project ID: 256065) and ethical approval was granted by the North West Greater Manchester Research Ethics Committee (REC reference 19/NW/0293) on 7 June 2019. Approval for the study to commence was given by the University of Manchester on 26 June 2019 (sponsor ref: NHS001546).

Provenance and peer review: Not commissioned; externally peer reviewed.

Data availability statement: Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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Appendix 1

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What do patients and carers want from online access to GP (Primary Care) records?

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Participant Information Sheet (PIS)

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12   You are being invited to take part in a research study to find out more about what patients and
13   carers want from online access to GP (Primary Care) records. Before you decide whether to take
14   part, it is important for you to understand why the research is being conducted and what it will
15   involve. Please take time to read the following information carefully before deciding whether to take
16   part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you
17   would like more information. Thank you for taking the time to read this.
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19
20   ## About the research
21
22
23   ➢ **Who will conduct the research?**
24
25   Dr Brian McMillan, Prof Caroline Sanders and Dr Gail Davidge (Division of Population Health, Health
26   Services Research and Primary Care, School of Health Sciences, University of Manchester) in
27   collaboration with Dr Helen Atherton (Warwick Medical School, University of Warwick) and Dr Freda
28   Mold (School of Health Sciences, University of Surrey).
29
30
31   ➢ **What is the purpose of the research?**
32
33   'Online access' refers to patients and their carers being able to access their GP record (or the record
34   of the person they care for) online. Research shows benefits of online access to records, for
35   example, people feel more in control and more able to communicate with healthcare staff. The
36   down sides include some professionals not being keen on the idea, people worrying about how
37   secure this is, or not always understanding what is in their record.
38
39
40
41   Research has mainly looked at the pros and cons of online access, or at how people look at their
42   record. More research is needed to find out how to design patient records to support people to stay
43   healthier for longer. For people to get the most out of being able to see their health record (or the
44   record of the person they care for) online, we need to understand more about what people actually
45   want from online access to records.
46
47   The study asks: What do people want from online access to their GP record (or the record of the
48   person they care for), what would they like to be able to do with this, and what help might they
49   need?
50
51
52   The study aims to talk to people to find out their views about online access. This will help to design
53   future online access services.
54
55
56   You have been chosen because you belong to one of the three groups of people we are interested
57   in: 1) healthy people aged 40-74 years, 2) people aged over 16 years with more than one long term
58
59
IRAS project ID 256065   **What do patients want from online access to their GP record?**
60   **Appendix 5: Participant Information Sheet**   **Version 4 03 July2019**

1

health condition, and 3) their carers. We chose these three groups as there is evidence they could benefit especially from online access to records. We are aiming to recruit a minimum of 50 participants in total.

➢ **Will the outcomes of the research be published?**

We will make the findings available to health care professionals, researchers, government representatives, and software companies who can all help shape and improve future online records access services. We will also publish the results in scientific journals and inform patient groups about the results. We will send you a summary of our findings if you request this.

➢ **Who has reviewed the research project?**

The project has been reviewed by the North West - Greater Manchester NHS Research Ethics Committee (reference number: 19/NW/0293).

➢ **Who is funding the research project?**

This study has been funded by the National Institute for Health Research School for Primary Care Research (SPCR-2014-10043: Grant reference number 429).

What would my involvement be?

➢ **What would I be asked to do if I took part?**

You will be invited to take part in either a focus group or a one-to-one interview to discuss your views about online access to GP records (a focus group is a group of around 6 people who sit in the same room and have a discussion guided by a researcher). Focus groups and interviews will last up to one hour and take place at times and in locations that are convenient to those taking part. We will audio-record these discussions so that we can fully consider and review all that is said. A University of Manchester approved supplier will type up the recordings before we analyse them in our research.

We recognise that some participants may feel upset if talking about difficult experiences. The researcher will be sensitive to this and will encourage people to take a break or possibly withdraw from the activity if the discussion becomes upsetting.

There are no immediate direct benefits to taking part, but you will have the opportunity to participate in research that aims to contribute to the improvement of services providing online access to GP records, which may personally benefit you in the future.

➢ **Will I be compensated for taking part?**

To say thanks for taking part in this study we will give you a £15 shopping voucher.

IRAS project ID 256065   What do patients want from online access to their GP record?
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2

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3 ➤ **What happens if I do not want to take part or if I change my mind?**
4
5 It is up to you to decide whether or not to take part. If you wish to take part please complete and
6 return the enclosed consent form in the envelope provided. If you decide to take part you are still
7
8 free to withdraw at any time without giving a reason and without detriment to yourself. However, it
9 will not be possible to remove your data from the project once it has been anonymised as we will
10 not be able to identify your specific data. This does not affect your data protection rights. If you
11 decide not to take part you do not need to do anything further. We plan to audio record the
12
13 interviews and focus group but you are free to decline to be recorded. Participants should be
14 comfortable with the recording process at all times and they are free to stop the recording at any
15 time.
16

Data Protection and Confidentiality

19
20
21 ➤ **What information will you collect about me?**
22
23 In order to participate in this research project we will need to collect information that could identify
24 you, called "personal identifiable information". Specifically we will need to collect:
25
26
27 • your name
28 • your contact details (telephone number, address, or e-mail address)
29
30 • your postcode
31 • your age
32 • your gender
33
34 • your ethnic group
35 • your level of education and occupation
36 • if you have any medical conditions (you don't have to tell us what they are)
37
38 • if you are a carer
39
40 The audio recordings will record voice only and will be obtained during focus groups and interviews.
41
42 ➤ **Under what legal basis are you collecting this information?**
43
44 We are collecting and storing this personal identifiable information in accordance with data
45 protection law which protect your rights. These state that we must have a legal basis (specific
46
47 reason) for collecting your data. For this study, the specific reason is that it is "a public interest task"
48 and "a process necessary for research purposes".
49
50 ➤ **What are my rights in relation to the information you will collect about me?**
51
52
53 You have a number of rights under data protection law regarding your personal information. For
54 example you can request a copy of the information we hold about you, including audio recordings. If
55 you would like to know more about your different rights or the way we use your personal
56
57 information to ensure we follow the law, please consult our Privacy Notice for Research
58 (http://documents.manchester.ac.uk/display.aspx?DocID=37095).
59

IRAS project ID 256065   **What do patients want from online access to their GP record?**
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> **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way.

Only the study team at The University of Manchester will have access to your personal information, but they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. Only the research team at the University of Manchester will have access to the key that links this ID number to your personal information. Your consent form and contact details will be retained in a locked filing cabinet until the end of the study so that we can send you a copy of the findings.

Potential disclosures:

If, during the study, we have concerns about your safety or the safety of others, we will ask you to discuss these with your GP. If, during the study, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities. Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

Audio recordings will be held on a University of Manchester approved encrypted recording device that can only be accessed using a PIN number until the researcher returns to the University (this will normally be on the same day). Audio recordings will be transferred from the recording device to secure University of Manchester Storage as soon as possible, checked and then deleted form the recording device. Recordings will be transcribed (typed up) in a secure environment by a University of Manchester approved transcription service. Any information that could identify you or anyone else you mention will be removed from transcriptions (such as names or reference to unusual conditions). Audio recordings will be destroyed as soon as possible after transcripts have been checked for accuracy.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

> **Contact details for complaints**

If you have a complaint that you wish to direct to members of the research team, please contact:

DR BRIAN MCMILLAN, e-mail: BRIAN.MCMILLAN@MANCHESTER.AC.UK, TEL: 0161 2757662

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For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

If we are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 2674 or 275 2046 or by email to research.complaints@manchester.ac.uk.

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Governance and Integrity Officer, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information (https://ico.org.uk/make-a-complaint/) Tel: 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact:

DR BRIAN MCMILLAN
CENTRE FOR PRIMARY CARE AND HEALTH SERVICES RESEARCH
UNIVERSITY OF MANCHESTER
WILLIAMSON BUILDING
OXFORD ROAD
MANCHESTER
M13 9PL

TEL: 0161 2757662
EMAIL: BRIAN.MCMILLAN@MANCHESTER.AC.UK

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For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Appendix 2

Topic Guide

Research aims:

Primary objective: To explore what two groups of primary care patients (those eligible for the NHS Health Check and those with multimorbidities), and their carers want from online access to their electronic primary care health record (GP record).

Secondary Objective: To examine how two groups of primary care patients (those eligible for the NHS Health Check and those with multimorbidities) and their carers would like to interact with their online primary care health record, and what support they may need

Introduction:
- Welcome
- Provide an outline of the study, including a definition of 'online access' – intended to stimulate conversation
- Recap details of participation
  - Voluntary (can withdraw any time)
  - Confidential
  - Audio recording of focus group and data protection (but will be anonymised)
  - Length of meeting – up to one hour

Ground rules:

We'd like you to do most of the talking

- We may ask your views if we've not heard from you in a while (but don't feel under pressure to say something if you don't want to)
- No need to discuss anything that makes you feel uncomfortable
- The importance of hearing everyone's views (try not to talk over each other, difficult to tell who's talking when listening back to the recording)
- There are no right or wrong answers (i.e. important to hear a full range of views)
- We should show each other respect even if we disagree
- What's shared in this room stays in this room (we will summarise findings without revealing anything that could identify an individual or anyone they discuss)
- Any questions?

Participant background:
- Ask each participant to introduce themselves
  - Consider only using their first name

Awareness of online access:

Ask for a show of hands – who has heard of online access?

  - Those who have - where did you hear about it?
    - What were your thoughts when you heard about it?

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Experience of online access:
- Ask for a show of hands - has anyone used online access at their GP practice?
  - Those who have
    - How easy was it to sign up?
    - What sort of things have you used it for?
    - How easy is it to use?

General views regarding online access (make sure to include those who have not heard of or used online access before):
- What do you think about the idea of online access generally?
  - Why?
  - What do you think are the pros (good points) and cons (bad points) about online access?
    - The benefits and disadvantages raised here should then be explored in greater depth

Needs and expectations regarding online access
This should flow from the previous conversations

- With regards to accessing your (/the person you care for) GP record online, <u>what</u> would you like to be able to do?
  - Use alternative phrasings if this does not stimulate conversation such as;
    - 'What features would you like to see in your (of the person you care for) online record?'

- With regards to accessing your (/the person you care for) GP record online, <u>how</u> would you like to be able to do it?
  - Use additional prompts if this does not stimulate conversation such as;
    - In the early days, some GP surgeries had kiosks installed in their waiting rooms where people could log in and see their record. What other ways you can think of that might be useful (e.g., equipment/space/support)?

- With regards to accessing your (/the person you care for) GP record online, <u>what sort</u> of support would you like?
  - Use additional prompts if this does not stimulate conversation such as;
    - Some people (/carers) might find it difficult to use online services; can you think of the sorts of things that might help them?

The future of online access
- With regards to access your (/the person you care for) GP record online, what sort of things do you imagine you might be able to do in the future?
  - (For possibilities raised) Do you think this is a good thing or a bad thing?
  - (For possibilities raised) Are there better ways this could be done?

Final thoughts
- Is there anything that anyone would like to add to the discussion?

Thank you for giving your time to discuss these issues

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	5
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The	5

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rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.

Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	6
Context	#7	Setting / site and salient contextual factors; rationale	5
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	5
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	17
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	6
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	6
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	6
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	6
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	6

Results/findings

Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	6
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	15

Discussion

Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	15
Limitations	#19	Trustworthiness and limitations of findings	16

Other

Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	n/a
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	17

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A qualitative exploration of patients' experiences, needs, and expectations regarding online access to their primary care record

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A qualitative exploration of patients' experiences, needs, and expectations regarding online access to their primary care record

Brian McMillan*[1], Gail Davidge[1], Lindsey Brown[1], Moira Lyons[1], Helen Atherton[2], Rebecca Goulding[1], Freda Mold[3], Rebecca Morris[1], Caroline Sanders[1]

1. Centre for Primary Care and Health Services Research, University of Manchester, UK

2. Warwick Medical School, University of Warwick, UK

3. School of Health Sciences, University of Surrey, UK

*Corresponding author: Dr Brian McMillan, Centre for Primary Care and Health Services Research, Suite 3, Floor 6, Williamson Building, Oxford Road, University of Manchester, England, M13 9PL. E-mail: brian.mcmillan@manchester.ac.uk Tel: 0161 2757656, Fax: 0161 2757600

Word count: 4212

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ABSTRACT

Objectives: Primary care records have traditionally served the needs and demands of clinicians rather than those of the patient. In England, General Practices must promote and offer registered patients online access to their primary care record, and research has shown benefits to both patients and clinicians of doing so. Despite this, we know little about patients' needs and expectations regarding online access to their record. This study explored what patients and carers want from online access to their electronic primary care health record, their experiences of using it, how they would like to interact with their record, and what support they may need.

Design: Focus groups and semi-structured interviews using purposive sampling to achieve a good sociodemographic spread. Interviews were digitally audio-recorded, transcribed and coded using an established thematic approach.

Setting: Focus groups and interviews were conducted in community settings in the UK.

Participants: Fifty-four individuals who were either eligible for the NHS Health Check, living with more than one long-term condition, or caring for someone else.

Results: Participants views regarding online access were categorised into 4 main themes: awareness, capabilities, consequences, and inevitability. Participants felt online access should be better promoted, and suggested a number of additional functions, such as better integration with other parts of the healthcare system. It was felt that online access could improve quality of care (e.g. through increased transparency) but also have potential negative consequences (e.g. by replacing face to face contact). A move towards more online records access was considered inevitable, but participants noted a need for additional support and training in using the online record, especially to ensure that health inequalities are not exacerbated.

Conclusions: Discussions with patients and carers about their views of accessing online records have provided useful insights into future directions and potential improvements for this service.

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Strengths and limitations of this study

- This is the first UK based study to explore the experiences, needs, and expectations of patients regarding online access to their primary care record, and to discuss the implications for the development of these services.

- Purposive sampling was employed to ensure a good sociodemographic mix, with individuals from urban and rural areas, and varying degrees of digital and health literacy.

- Patient and public participation in the research ensured it remained patient focussed and included views from seldom-heard groups.

- A mixture of focus groups and one to one interviews enabled exploration of shared experiences and understandings whilst also allowing further probing of minority or controversial opinions and discussion of sensitive issues.

- Potential limitations include the absence of participant validation, and the need for exploration of transferability of findings to different international healthcare settings, which may facilitate the development of a theoretical framework.

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INTRODUCTION

The GP Contract in England states all patients should have online access to their full primary care record. [1] Whilst this has not been fully implemented, 24% of patients in England have signed up for online records access (ORA)[2] via the NHS App or other NHS-approved service.[3] Systematic reviews examining ORA have identified a number of potential benefits and drawbacks.[4, 5, 6] Patients can use ORA as an aide-mémoire, to help prepare for their next appointment,[7, 8, 9] and report that it saves time by reducing the number of telephone calls and appointments required.[4, 7] ORA can increase patients' feelings of autonomy,[10, 11] enable them to spot and correct medication errors,[4, 6] and positively impacts on clinical measures such as HbA1c.[6] However, clinicians have expressed concerns that ORA could cause unnecessary anxiety, increase complaints, and threaten confidentiality and security. [5] Other concerns relate to: widening health inequalities, risk of coercion, and increased clinician workload.[12]

Research has looked at what patients do with ORA and its impact on patient satisfaction and engagement. However, there has been little research examining what patients *want* from ORA. Overlooking patients' needs and expectations may prevent patient ORA from achieving its full potential. Only three qualitative studies have examined what patients want from ORA,[13, 14, 15] indicating they want it to: 1) be secure and trustworthy, 2) act as a communication aid, 3) be more interactive, 4) serve an educational function, 5) serve practical functions. These studies identified the importance of ORA aiding communication between patients and healthcare professionals (HCPs), other family members, carers, or between HCPs. Patients would like to be able to write into their record,[14, 15] and expressed a desire for decision aids,[13] and lifestyle management with signposting to services.[13, 14] Sought after educational functions included plain English explanations of medical terms,[14, 15] and practical functions including booking appointments,[14] viewing test results,[14, 15] and accessing information needed to complete benefit applications.[14]

Although these qualitative studies have started to identify what patients want from ORA, only one was primary care based and conducted in the UK, and was carried out over 16 years ago examining a significantly different service than is available today.[15] The authors noted that "working in partnership with patients to develop systems is essential to their

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success".[15, p38] To achieve this, we need to ascertain what patients would like from ORA rather than simply asking them to evaluate systems that already exist.

Through our Patient and Public Involvement and Engagement (PPIE) work[16] and previous reviews,[4, 17, 18] we identified three diverse groups likely to have different needs and expectations of ORA: those eligible for the NHS Health Check[19] who value ORA to understand how they might maintain good health[16] and those with multimorbidities and carers, who value it for managing their conditions or the conditions of those they care for.[4] This study therefore aims to explore patients' and carers'

- awareness and experiences of ORA
- views and beliefs regarding ORA
- expressed needs and expectations regarding ORA, including required support.

METHODS

Given the limitations of the existing evidence base in this area, an exploratory qualitative study, informed by grounded theory, was conducted. Data were collected through focus groups and semi-structured interviews in community settings in the UK, followed by an inductive thematic analysis [20].

Sampling and recruitment

A purposive sampling strategy was employed to achieve maximum variability for factors known to impact ORA, such as age, sex, socioeconomic status, and ethnicity.[21] Recruitment methods included utilising the Greater Manchester Clinical Research Network (CRN), approaching community organizations, and snowballing. A participant information leaflet described the study in detail and listed the eligibility criteria (see Appendix 1). Informed written consent was obtained, and focus groups were held until the research team considered that data saturation was approaching as no new themes were being identified,[20] at which point recruitment switched to semi-structured interviews to explore issues raised in greater depth. Participants who were interviewed had not previously participated in the focus groups. Recruitment ceased when no further new or discordant

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themes were identified.

Data collection methods

A total of 11 focus groups and 9 interviews were conducted independently by two of the authors (BM and GD). The topic guide (Appendix 2) covered five main areas regarding ORA: awareness; experiences; views; needs and expectations; and perceptions of the future. The same topic guide was used for both focus groups and interviews. The focus groups and interviews lasted 30-60 minutes, were digitally audio recorded, and transcribed by a university approved service.

Patient and public involvement

The topic guide was developed following observations of clinical consultations at a practice where patients have full ORA, a patient and public involvement and engagement (PPIE) workshop,[16] and discussions with the Primary Care Research in Manchester Engagement Resource (PRIMER) group, two members of which are co-authors of this paper (LB & ML).

Data analysis

Transcripts were anonymised, imported into QSR NVivo 12,[22] and checked for accuracy. BM and GD independently coded the transcripts, using the thematic analysis approach , which involved six phases; data familiarization; coding; identification of candidate themes; review and revision of themes; definition and naming of themes; analysis and interpretation of patterns across the data.[20] Although the traditional concept of validity is problematic in qualitative research [20], discussions amongst the research team helped identify key issues, verify themes, and ensure consistency of coding. In addition, we sought to enhance dependability of our findings by involving two members of the public (LB, ML) in two half-day workshops during which we refined the themes using Ketso, a toolkit for creative engagement.[23] .

RESULTS

Demographics

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A total of 27 women and 27 men aged between 21 and 87 years (mean = 59.0; SD = 15.4) participated from a wide range of socioeconomic backgrounds.[24] We conducted 11 focus groups totalling 45 participants (with 3 to 6 participants per group), and 9 individual interviews (see Table 1).

Themes

Patients' and carers' views of ORA concerned four main themes: *1. Awareness, 2. Capabilities*, *3. Consequences*, and *4. Inevitability*.

1. Awareness of online records access

Less than half the participants were aware of ORA. Those who were reported it had been promoted by their GP surgery or had heard of it by word of mouth. Some felt they had no reason to use ORA, found it easier to find information by other means, or felt accessing

Table 1. Participant demographic characteristics (N=54)

Characteristic	n	%
Self-identify as carer	19	35.2
>1 long-term medical condition	24	44.4
Eligible for NHS Health Check	30	55.6
Aware of ORA	23	42.6
Previously used ORA	10	18.5
Frequency of internet usage		
Frequently	41	75.9
Occasionally	10	18.5
Never	3	5.6
Ethnicity		
White	43	79.6
Asian	4	7.4
Black	7	13.0
Education		
Degree level	12	22.2
Further education	7	13.0
School to 16 years of age	25	46.3
School to ≤ 16 years of age	10	18.5
Occupation		
Retired	19	35.2
Professional	8	14.8
Sales/customer service	4	7.4
Caring/leisure/other	13	24.1

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Admin/secretarial	1	1.9
Associate/technical	2	3.7
Self-employed	3	5.6
Not working	4	7.4
Index of multiple deprivation [24]		
Deciles 1-3 (most deprived)	16	29.6
Deciles 4-7	17	31.5
Deciles 8-10 (least deprived)	21	38.9
Rural-urban classification [25]		
Urban	32	59.2
Suburban	9	16.7
Rural	13	24.1

medical records was best left to HCPs. Some expressed annoyance that they had not been informed about ORA, whilst others stated that learning about the service had not made them any more likely to use it. Participants felt ORA was poorly advertised, and suggested promoting it via media advertisements, posters in surgeries, and during GP consultations.

2. Capabilities of online records access

Access to information

Participants reported ORA enabled them to view: test results, medication lists, allergies, immunizations, appointment details, problem lists, secondary care letters, and consultation notes, but expressed dissatisfaction with the content, detail, and presentation of the information. Suggested improvements included: direct links to sources of support, more information about the HCPs providing care, better integration with other services, full retrospective access, easier and more consistent access to information, use of plain English, and links to trusted sources of information. Several wished to access all their health and care records via one fully integrated system.

Enabling active involvement

Participants who had used ORA noted that it enabled them to be more actively involved in their own health and care, and those who had not felt it could, by facilitating: self-monitoring, self-education (e.g. looking up meanings of terms seen in record), self-reassurance, appointment preparation, use of the record as an aide-mémoire or

motivational tool, paperwork completion, communication with HCPs when away from home, and addressing dissatisfaction with care. Examples of using ORA to self-motivate and self-monitor included tracking blood glucose, weight loss, or cholesterol.

"when people have got something like that, to lose weight and to watch their cholesterol, I think by having something online, it's something for them to go to and check, I don't know, daily, weekly, monthly, whatever they want to do, it just gives them a bit more motivation." (Interview; P45)

Interactive capabilities

Participants reported finding interactive capabilities of ORA systems useful, especially appointment booking, and ordering prescriptions, but found difficulties with basic interactive functions (e.g. login, printing, searching, downloading information). Some valued being able to book appointments online as an alternative to having to explain reasons for appointment requests to receptionists.

"I rang the surgery, they said, no, there's nothing for two weeks, or whatever. My sister, who's on it, said, use your patient access, because I'd forgotten. I went on and I was able to book an appointment for the next day". (Focus Group (FG); P32)

Participants reported that ORA could make their role as a carer easier by acting as an aide memoire, giving them more control over medications, reminding parents when their child's immunizations were due, or helping complete benefit applications.

"I help her to fill in her PIP forms and things like that, and it was an absolute nightmare back and forward, back and forward to the GP … if I could have accessed that on her behalf, it would have been a million times easier" (FG; P52)

Suggested improvements to interactive capabilities included more advanced login methods, a triage feature for online appointment booking, medication reminders, and pharmacy stock checks.

"I'd much prefer that it loaded up on the app that I need whatever antibiotic as soon

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> *as I leave the GP, tap it, it says it's in stock at your specific pharmacy. Amazon have,*
>
> *like, 'there's 15 of these in stock' " (Interview; P45)*

3. Consequences of online access to records

Patient safety

Participants noted that ORA could improve safety by reducing the likelihood that test results would go unnoticed, or enabling them to spot errors in their record.

> *"I had to correct, both on the dates and on the data… because if, for example, I get*
>
> *taken to hospital and the hospital can access this and they're going to make decisions*
>
> *based on the evidence that they see in front of them … that might affect my life" (FG;*
>
> *P19)*

Others noted however that ORA could negatively impact patient safety by encouraging unreliable self-diagnosis, self-medication, or discouraging HCPs from documenting concerns regarding issues such as mental health or abuse, for fear of upsetting patients.

Communication between HCPs

Concerns such as those raised above could impact negatively on communication between HCPs, and there was some discussion about how this could be addressed.

> *"you wouldn't want to be doubling any doctor's workload in terms of writing an*
>
> *account that's for the patient and writing an account that's for another professional*
>
> *to read, but I'm not sure that one could always serve both" (FG; P22)*

It was however felt that ORA could aid communication between HCPs indirectly by giving patients the ability to show HCPs not usually involved in their care their medical notes whilst away from home. Participants suggested communication between HCPs could be improved further by greater integration of primary, secondary, and community health care records.

The HCP-patient relationship

Participants felt ORA could foster a culture of openness, improve communication, and

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increase accountability.

> *"your MP [Member of Parliament], or whatever, they're all accountable, we can look up what they're saying and all that, why not my GP?" (FG; P30)*

Participants also noted that having access to hospital letters could improve communication by empowering them to question conflicting advice. Greater transparency from ORA could also raise standards of care by enabling holding HCPs to account.

> *"it would improve standards that way because doctors would know what they write is there for everyone to see" (Interview; P36)*

Some worried that ORA could replace face to face contact with HCPs or increase social isolation.

> *"don't do it by computer, just go down yourself and order it and make a day out of it. Take your friend, go to the bar, have a snack or a cup of coffee … it keeps you out of the house" (FG; P15)*

Test results

A common concern was that test results which may previously have been cautiously explained during consultations could be viewed by patients before there was a chance to discuss them.

> *"if you get a really bad test result sometimes the doctor can kind of reassure you about ways that they can help you, but if you just find out about it you might just completely worry about it" (Interview; P53)*

Proposed solutions included entries about results being written in plain English or for patients to have 'write' access to their notes to instigate dialogue, with some participants suggesting enabling patients to share information from wearables or the 'internet of things'. Solutions proposed to address the issue of test results causing anxiety included systems ensuring patients could not see results until they had first been viewed by a clinician, although some were conflicted.

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"I'd want to see them straight away … I don't necessarily think that would be a beneficial thing to do though, I think obviously once the doctor's interpreted it, they can sort of let you know what you need to know in a way that you need to know it. I mean, I get anxious around health things anyway" (FG; P50)

One participant proposed a built-in feature to enable identification of individuals for whom ORA may be causing anxiety.

"Because that would be a failsafe thing if you had someone who was constantly and obviously very anxiously accessing their records, that should flag up that that person needs to have a conversation" (FG; P23)

Health inequalities

Participants noted how ORA could lessen health inequalities. For example, one wheelchair user noted that online access could improve their access to healthcare, others living in rural areas noted similar benefits.

"there's no point driving ten miles, to ask one question, when you could do it online in two minutes". (Interview; P45)

There were significant concerns however that ORA could exacerbate health inequalities. Digital literacy was a particular concern, especially as surgery staff were not always able to help. In addition, those who are reliant on using computers and free WiFi in public spaces may be disadvantaged in terms of privacy. Concerns were also voiced regarding general literacy, not speaking English as a first language, and identification required to register.

Participants suggested addressing inequalities in digital literacy by providing training, either at GP surgeries or community locations, as well as access to resources.

"..have a list of places that people can go for help… or even have an open day or an hour, just for people to take that information when they register, and then maybe someone there to show them how to use it". (FG; P32)

Literacy and language issues could be partially mitigated by incorporating a 'medical

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dictionary' and translate function, or providing training for GPs on writing consultation notes. Participants also suggested that problems related to registration could be addressed by simplifying the paperwork and extending the types of identification accepted.

Confidentiality and security

Whilst many participants felt that the security of ORA was adequate, others expressed serious concerns. Those with the strongest objections to ORA tended to be older, have less confidence in using the internet, and felt older people might be more likely to be targeted by fraudsters. Concerns were also raised about unwanted access due to the coercion of an abusive partner or employer.

> *"if someone phones in sick for work and their employer for whatever reason challenges them … Is the employer going to then, sort of, force this person to basically hand over their phone and [say] 'I'll just have a look, make sure you've been to the doctor'?…" (FG; P51)*

A number of participants also highlighted anxieties about data sharing with private companies, or that security can be affected by simple user oversights, such as not password protecting a mobile phone. Most participants indicated that measures such as two-factor authentication or biometric access would make them feel more confident. Others stated that they would like control over who can access which parts of their record. This included proxy access (permitted access by a relative or carer) and the ability to revoke such access easily in the future.

> *"would I want my immediate family reading what I've said? … I think it might have to be potentially an option within the system to say that that individual can have access to certain aspects of my records but not the entire thing" (Interview; P37)*

Impact on resource allocation

Participants generally felt ORA could reduce the need to travel to appointments or spend time in long telephone queues.

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"I was on the phone for ages, I couldn't get through…I needed my blood results because I was going to an appointment, so I ended up jumping in the car, driving down and saying, can you please…and they printed it out and gave it to me. So yeah, I could have just literally tabbed on and printed it out myself" (Interview; P37)

"There might be issues where it's a simple question to a GP that could just be a text and a text back, job done, rather than setting up a whole appointment" (Interview; P44)

There were mixed views regarding the impact of ORA on primary care staff resource allocation. Participants suggested it could reduce demand for GP appointments and reduce practice workload. It was also felt ORA might prompt preventative action from patients which could further reduce pressures on primary care. Despite these positives, there were concerns that ORA could increase HCP workload in a variety of ways such as prompting patients to call practices to discuss test results they had seen but not understood, or GPs needing to spend more time documenting consultations.

4. Inevitability of shift towards online services

Whilst there was some resistance to the move towards online services, especially amongst some of the older participants and those from ethnic minority groups, there was an acknowledgement that much personal data is already held online.

"Our records are online anyway, aren't they, really? Everything's online already …so it's just really us being able to get access to it really" (FG; P40)

Participants compared ORA with previous transformational societal changes, such as: the postal system, aviation, and online banking.

"Yeah, I do online banking. You're not forced to do it these days, but that seems to be the way that everything's going, so you've kind of got to roll with it" (Interview; P45)

Several participants noted generational differences in terms of acceptance of ORA, and one

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discussion focussed on how those who resist services such as ORA tend to be older, and are gradually being replaced by more technologically-savvy generations.

> *"It will become much more universal that everybody knows that you have to access the internet in order to live a normal life, and the older people who still won't look at it won't be here forever, probably." (FG; P9)*

DISCUSSION

Participants saw both benefits and drawbacks to ORA, but a move towards more online health services was considered inevitable. The results of this study highlight a range of ways in which ORA can be promoted to those who lack awareness of, or motivation to use, this service. It has shown how systems could be improved to better meet the needs and preferences of patients, address their concerns about privacy and security, increase patient involvement in care, strengthen relationships between patients and care providers, and reduce risks to patient safety. Additionally, whilst ORA has the potential to exacerbate health inequalities, it may also decrease them, especially where training or facilities are made available, and consultation summaries and interpretations of test results are written in plain English.

Comparison with existing literature

Our findings resonate with previous qualitative work in this area.[9, 10, 13, 14, 15] Concerns regarding security and trustworthiness, and ORA acting as a communication aid were discussed in our *consequences* theme. ORA providing greater interactivity, and serving educational and practical functions were topics discussed in our *capabilities* theme. In line with previous studies,[9, 10, 14, 15] instant access to test results was listed as both a benefit (e.g. in terms of convenience) and a drawback (e.g. the potential to cause unnecessary anxiety), prompting suggestions for improvement such as plain English definitions or pre-screening of results by clinicians. Our study has updated this knowledge and cast further light on what patients want from ORA in primary care. Unlike previous work in this area, which was concerned with evaluating pre-existing [10, 13, 15] or tertiary care systems for specific conditions,[14] our study examined people's views regarding ORA in primary care, and what features and functions patients would like to see in such systems in the future.

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This work compliments a recent systematic review in this area demonstrating the clinical benefit of online access [6] by providing in-depth insights into how we might further increase patient engagement.

This study contains a number of novel findings regarding the needs and expectations of patients and carers with respect to ORA. Many people are still unaware this service exists [26] and it needs to be better promoted if the UK government's vision is to be realised. It has also revealed an understandable desire for greater consistency across time and between users in terms of what people can actually see with ORA. Interesting suggestions regarding the capabilities of ORA systems include incorporating the ability for patients to check if their pharmacy is out of stock of their medication; this issue has become particularly troublesome for primary care patients in recent years.[27] Our findings regarding patients' wishes to integrate online records systems with wearable devices are also novel, as are suggestions to provide a greater degree of control over who can access one's record and the ability to set varying levels of access to different third parties. Such features are commonplace on social media platforms such as Facebook. The suggestion of allowing patients to request different modes of appointment (i.e. telephone, video, face to face) is especially interesting given recent changes to the way GPs are working in light of the coronavirus pandemic.

Strengths and limitations

The strengths of this study include the diversity of the sample in terms of age, socioeconomic status and ethnicity, and the inclusion of participants from seldom heard communities. Such individuals are more likely to be affected by issues such as health inequalities and the 'digital divide'.[28]

Limitations to this study include the fact that we did not validate our findings with study participants and the researchers' backgrounds may have influenced the dynamic of the interviews and subsequent findings. Despite this, consideration of reflexivity, and discussions with the rest of the research team, including two members of the public, helped to avoid an overly narrow interpretation of the findings. Also, the study examined the views of participants regarding ORA, rather than making observations of their actual behaviour. We took the commonly adopted critical realist perspective, which holds that some degree of

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truth can be ascertained through the examination of qualitative data, whilst acknowledging that this is nuanced by human interpretation.[20] Lastly, this exploratory study has not delivered a theoretical framework, but was designed to identify patients' experiences, needs and expectations regarding online access to their primary care record in the UK. Future qualitative work could explore the transferability of our findings to other healthcare systems and settings, and planned feasibility work will cast more light upon the impact of incorporating participants' suggested improvements into ORA systems. Future quantitative research studies could also further explore differences in views and behaviour with respect to online records access between different socio-demographic groups.

Implications for policy, practice and research

If we are to fulfil the UK Government's expectations that all patients should have online access to their full primary care record, [29] we will need to ensure that online access is better promoted. As more patients start using ORA, we will also need to provide better support for patients and carers to get the most out of this service as well as additional training for practice staff.

Although patients have had the statutory right to access to their medical records since 1991,[30] HCPs now need to be even more mindful of the fact that their entries may be viewed by patients. GPs and other HCPs will need to adapt the way they write in the record so that it can be easily understood by patients, as not doing so may result in an increased workload due to more patient enquires. HCPs will also need to ensure that systems are in place to communicate concerns regarding sensitive issues such as safeguarding or domestic abuse to other HCPs without compromising the HCP-patient relationship or putting patients at risk.

If we are to meet patient expectations regarding ORA, we need to go beyond simply enabling patients to view information. We should aim to collaborate with patients, carers, clinicians, the IT industry, behaviour change experts, policymakers, and the NHS to shape the online record into an interactive tool than can motivate, educate, and provide the opportunity for patients to become more engaged in their own healthcare. This will provide a new set of challenges, such as developing accreditation to ensure that the data provided by wearables is accurate and reliable. We also need to be mindful that the shift towards

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more provision of services via online systems does not exacerbate health inequalities.

Footnotes

Author Contributions: BM conceived the original idea for the study. BM, LB, ML, HA, RG, FM, RM & CS developed the study design, obtained funding, and refined the study protocol. BM and GD undertook data collection. BM and GD undertook analysis and interpretation with contributions from all co-authors. All co-authors prepared the manuscript. All authors read and approved the final manuscript.

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Competing interests: None declared

Ethics approval: NHS Health Research Authority Approval was applied for through the IRAS online form (IRAS Project ID: 256065) and ethical approval was granted by the North West Greater Manchester Research Ethics Committee (REC reference 19/NW/0293) on 7 June 2019. Approval for the study to commence was given by the University of Manchester on 26 June 2019 (sponsor ref: NHS001546).

Provenance and peer review: Not commissioned; externally peer reviewed.

Data availability statement: Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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Appendix 1

What do patients and carers want from online access to GP (Primary Care) records?

Participant Information Sheet (PIS)

You are being invited to take part in a research study to find out more about what patients and carers want from online access to GP (Primary Care) records. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

➢ **Who will conduct the research?**

Dr Brian McMillan, Prof Caroline Sanders and Dr Gail Davidge (Division of Population Health, Health Services Research and Primary Care, School of Health Sciences, University of Manchester) in collaboration with Dr Helen Atherton (Warwick Medical School, University of Warwick) and Dr Freda Mold (School of Health Sciences, University of Surrey).

➢ **What is the purpose of the research?**

'Online access' refers to patients and their carers being able to access their GP record (or the record of the person they care for) online. Research shows benefits of online access to records, for example, people feel more in control and more able to communicate with healthcare staff. The down sides include some professionals not being keen on the idea, people worrying about how secure this is, or not always understanding what is in their record.

Research has mainly looked at the pros and cons of online access, or at how people look at their record. More research is needed to find out how to design patient records to support people to stay healthier for longer. For people to get the most out of being able to see their health record (or the record of the person they care for) online, we need to understand more about what people actually want from online access to records.

The study asks: What do people want from online access to their GP record (or the record of the person they care for), what would they like to be able to do with this, and what help might they need?

The study aims to talk to people to find out their views about online access. This will help to design future online access services.

You have been chosen because you belong to one of the three groups of people we are interested in: 1) healthy people aged 40-74 years, 2) people aged over 16 years with more than one long term

health condition, and 3) their carers. We chose these three groups as there is evidence they could benefit especially from online access to records. We are aiming to recruit a minimum of 50 participants in total.

➢ **Will the outcomes of the research be published?**

We will make the findings available to health care professionals, researchers, government representatives, and software companies who can all help shape and improve future online records access services. We will also publish the results in scientific journals and inform patient groups about the results. We will send you a summary of our findings if you request this.

➢ **Who has reviewed the research project?**

The project has been reviewed by the North West - Greater Manchester NHS Research Ethics Committee (reference number: 19/NW/0293).

➢ **Who is funding the research project?**

This study has been funded by the National Institute for Health Research School for Primary Care Research (SPCR-2014-10043: Grant reference number 429).

What would my involvement be?

➢ **What would I be asked to do if I took part?**

You will be invited to take part in either a focus group or a one-to-one interview to discuss your views about online access to GP records (a focus group is a group of around 6 people who sit in the same room and have a discussion guided by a researcher). Focus groups and interviews will last up to one hour and take place at times and in locations that are convenient to those taking part. We will audio-record these discussions so that we can fully consider and review all that is said. A University of Manchester approved supplier will type up the recordings before we analyse them in our research.

We recognise that some participants may feel upset if talking about difficult experiences. The researcher will be sensitive to this and will encourage people to take a break or possibly withdraw from the activity if the discussion becomes upsetting.

There are no immediate direct benefits to taking part, but you will have the opportunity to participate in research that aims to contribute to the improvement of services providing online access to GP records, which may personally benefit you in the future.

➢ **Will I be compensated for taking part?**

To say thanks for taking part in this study we will give you a £15 shopping voucher.

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3   ➢ **What happens if I do not want to take part or if I change my mind?**
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5   It is up to you to decide whether or not to take part. If you wish to take part please complete and
6   return the enclosed consent form in the envelope provided. If you decide to take part you are still
7   free to withdraw at any time without giving a reason and without detriment to yourself. However, it
8   will not be possible to remove your data from the project once it has been anonymised as we will
9   not be able to identify your specific data. This does not affect your data protection rights. If you
10   decide not to take part you do not need to do anything further. We plan to audio record the
11   interviews and focus group but you are free to decline to be recorded. Participants should be
12   comfortable with the recording process at all times and they are free to stop the recording at any
13   time.
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16
17   ## Data Protection and Confidentiality
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20   ➢ **What information will you collect about me?**
21
22   In order to participate in this research project we will need to collect information that could identify
23   you, called "personal identifiable information". Specifically we will need to collect:
24
25
26   • your name
27   • your contact details (telephone number, address, or e-mail address)
28   • your postcode
29   • your age
30   • your gender
31   • your ethnic group
32   • your level of education and occupation
33   • if you have any medical conditions (you don't have to tell us what they are)
34   • if you are a carer
35
36   The audio recordings will record voice only and will be obtained during focus groups and interviews.
37
38   ➢ **Under what legal basis are you collecting this information?**
39
40   We are collecting and storing this personal identifiable information in accordance with data
41   protection law which protect your rights. These state that we must have a legal basis (specific
42   reason) for collecting your data. For this study, the specific reason is that it is "a public interest task"
43   and "a process necessary for research purposes".
44
45   ➢ **What are my rights in relation to the information you will collect about me?**
46
47   You have a number of rights under data protection law regarding your personal information. For
48   example you can request a copy of the information we hold about you, including audio recordings. If
49   you would like to know more about your different rights or the way we use your personal
50   information to ensure we follow the law, please consult our Privacy Notice for Research
51   (http://documents.manchester.ac.uk/display.aspx?DocID=37095).

IRAS project ID 256065   **What do patients want from online access to their GP record?**
Appendix 5: Participant Information Sheet   **Version 4 03 July2019**

3

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

> **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way.

Only the study team at The University of Manchester will have access to your personal information, but they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. Only the research team at the University of Manchester will have access to the key that links this ID number to your personal information. Your consent form and contact details will be retained in a locked filing cabinet until the end of the study so that we can send you a copy of the findings.

Potential disclosures:

If, during the study, we have concerns about your safety or the safety of others, we will ask you to discuss these with your GP. If, during the study, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities. Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

Audio recordings will be held on a University of Manchester approved encrypted recording device that can only be accessed using a PIN number until the researcher returns to the University (this will normally be on the same day). Audio recordings will be transferred from the recording device to secure University of Manchester Storage as soon as possible, checked and then deleted form the recording device. Recordings will be transcribed (typed up) in a secure environment by a University of Manchester approved transcription service. Any information that could identify you or anyone else you mention will be removed from transcriptions (such as names or reference to unusual conditions). Audio recordings will be destroyed as soon as possible after transcripts have been checked for accuracy.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

> **Contact details for complaints**

If you have a complaint that you wish to direct to members of the research team, please contact:

DR BRIAN MCMILLAN, e-mail: BRIAN.MCMILLAN@MANCHESTER.AC.UK, TEL: 0161 2757662

IRAS project ID 256065   What do patients want from online access to their GP record?
Appendix 5: Participant Information Sheet   Version 4 03 July2019

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For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

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3   If we are unable to resolve your concern or you wish to make a complaint regarding the study,
4   please contact a University Research Practice and Governance Co-ordinator on 0161 275 2674 or
5   275 2046 or by email to research.complaints@manchester.ac.uk.
6
7
8   **If you wish to make a formal complaint to someone independent of the research team or if you**
9   **are not satisfied with the response you have gained from the researchers in the first instance then**
10   **please contact**
11
12
13   The Research Governance and Integrity Officer, Research Office, Christie Building, The University of
14   Manchester, Oxford Road, Manchester, M13 9PL, by emailing:
15   research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.
16
17   If you wish to contact us about your data protection rights, please email
18   dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building,
19   The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you
20   through the process of exercising your rights.
21
22   You also have a right to complain to the Information Commissioner's Office about complaints
23   relating to your personal identifiable information (https://ico.org.uk/make-a-complaint/)
24   Tel: 0303 123 1113
25
26   ## Contact Details
27
28   If you have any queries about the study or if you are interested in taking part then please contact:
29
30   **DR BRIAN MCMILLAN**
31   **CENTRE FOR PRIMARY CARE AND HEALTH SERVICES RESEARCH**
32   **UNIVERSITY OF MANCHESTER**
33   **WILLIAMSON BUILDING**
34   **OXFORD ROAD**
35   **MANCHESTER**
36   **M13 9PL**
37
38   **TEL: 0161 2757662**
39   **EMAIL: BRIAN.MCMILLAN@MANCHESTER.AC.UK**
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The University of Manchester

Appendix 2

Topic Guide

Research aims:

Primary objective: To explore what two groups of primary care patients (those eligible for the NHS Health Check and those with multimorbidities), and their carers want from online access to their electronic primary care health record (GP record).

Secondary Objective: To examine how two groups of primary care patients (those eligible for the NHS Health Check and those with multimorbidities) and their carers would like to interact with their online primary care health record, and what support they may need

Introduction:
- – Welcome
- – Provide an outline of the study, including a definition of 'online access' – intended to stimulate conversation
- – Recap details of participation
    - – Voluntary (can withdraw any time)
    - – Confidential
    - – Audio recording of focus group and data protection (but will be anonymised)
    - – Length of meeting – up to one hour

Ground rules:

We'd like you to do most of the talking

- – We may ask your views if we've not heard from you in a while (but don't feel under pressure to say something if you don't want to)
- – No need to discuss anything that makes you feel uncomfortable
- – The importance of hearing everyone's views (try not to talk over each other, difficult to tell who's talking when listening back to the recording)
- – There are no right or wrong answers (i.e. important to hear a full range of views)
- – We should show each other respect even if we disagree
- – What's shared in this room stays in this room (we will summarise findings without revealing anything that could identify an individual or anyone they discuss)
- – Any questions?

Participant background:
- • Ask each participant to introduce themselves
    - o Consider only using their first name

Awareness of online access:

Ask for a show of hands – who has heard of online access?

- o Those who have - where did you hear about it?
    - ▪ What were your thoughts when you heard about it?

Experience of online access:
- Ask for a show of hands - has anyone used online access at their GP practice?
  - Those who have
    - How easy was it to sign up?
    - What sort of things have you used it for?
    - How easy is it to use?

General views regarding online access (make sure to include those who have not heard of or used online access before):
- What do you think about the idea of online access generally?
  - Why?
  - What do you think are the pros (good points) and cons (bad points) about online access?
    - The benefits and disadvantages raised here should then be explored in greater depth

Needs and expectations regarding online access
This should flow from the previous conversations

- With regards to accessing your (/the person you care for) GP record online, <u>what</u> would you like to be able to do?
  - Use alternative phrasings if this does not stimulate conversation such as;
    - 'What features would you like to see in your (of the person you care for) online record?'

- With regards to accessing your (/the person you care for) GP record online, <u>how</u> would you like to be able to do it?
  - Use additional prompts if this does not stimulate conversation such as;
    - In the early days, some GP surgeries had kiosks installed in their waiting rooms where people could log in and see their record. What other ways you can think of that might be useful (e.g., equipment/space/support)?

- With regards to accessing your (/the person you care for) GP record online, <u>what sort</u> of support would you like?
  - Use additional prompts if this does not stimulate conversation such as;
    - Some people (/carers) might find it difficult to use online services; can you think of the sorts of things that might help them?

The future of online access
- With regards to access your (/the person you care for) GP record online, what sort of things do you imagine you might be able to do in the future?
  - (For possibilities raised) Do you think this is a good thing or a bad thing?
  - (For possibilities raised) Are there better ways this could be done?

Final thoughts
- Is there anything that anyone would like to add to the discussion?

Thank you for giving your time to discuss these issues

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	5
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The	5

rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.

Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	6
Context	#7	Setting / site and salient contextual factors; rationale	5
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	5
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	17
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	6
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	6
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	6
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	6
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	6

Results/findings

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| Syntheses and interpretation | #16 | Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 6 |
| Links to empirical data | #17 | Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 15 |

Discussion

| Intergration with prior work, implications, transferability and contribution(s) to the field | #18 | Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field | 15 |
| Limitations | #19 | Trustworthiness and limitations of findings | 16 |

Other

| Conflicts of interest | #20 | Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed | n/a |
| Funding | #21 | Sources of funding and other support; role of funders in data collection, interpretation and reporting | 17 |

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